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Enhancing Survivorship:

An Evaluation of Social/Emotional Training for Facilitators of the **LIVESTRONG** at the YMCA

Program

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Abstract

Introduction: Cancer survivorship groups are able to provide a safe space for those who are battling cancer and for those in remission. Facilitators of these programs are reaching emotional thresholds where they feel ill equipped to handle the psychological needs of group participants. **Purpose:** The purpose of this study is to evaluate the social/emotional training provided to facilitators of the LIVESTRONG at the YMCA program. **Methods:** Pre and post surveys were administered to nine training participants in order to assess their feelings and perceptions of social and emotional wellness before and after participating in the training. Follow-up interviews were conducted four weeks after program training in order to further evaluate the implementation of the training into the program. **Results:** Descriptive statistics showed that facilitators are knowledgeable in the significance of social/emotional health, survivor and survivor wellness, and the phases of cancer, but reported limited knowledge in accessing resources to handle emotional overload. Post follow-up interviews with study participants confirmed the following themes toward further expansion of wellness trainings into the program: social/emotional support strategies, incorporating participant connectedness, and establishing self-care. **Discussion:** Major findings of the study concluded that the participants, as facilitators, felt that they need more support and training towards how to cope with the emotional overload that coincides with working with those living as survivors. **Conclusion:** The social/emotional training intervention, supports the need for facilitators of the LIVESTRONG program at the YMCA to be provided the skills necessary to defer the detriments of emotional labor.

Introduction

Diagnosis of disease can alter an individual's life in a matter of seconds. There may have been warning signs, or none at all, but the fear of confirming a diagnosis is impossible to fathom. Chronic disease affects an individual physically, emotionally and mentally; making support a critical aspect of the treatment and healing process. Specifically, in cancer treatment, social support plays a vital role for the patient to feel validated that they are cared for and have others to lean on during this difficult time.

Maintaining a healthy lifestyle following treatment is critical for a patient to sustain their health. Physical activity, diet and adequate sleep are ways in which cancer survivors can regain their health and prevent the recurrence of disease. This is certainly not a simple transition as one's body has experienced a multitude of medications and treatments that have caused serious alterations to their body composition and overall strength. Seeking out wellness programs can be a major asset for cancer survivors who are still receiving treatment or are in remission. It not only gets them up and active, but it also provides them the opportunity to build relationships with other survivors. **LIVESTRONG** at the YMCA provides cancer survivors the opportunity to enroll in a free, 12-week physical activity program. This program highlights the significance of exercise post-treatment, as well as an emphasis on building healthy relationships with others who have also travelled down the long road of living with cancer.

The success of the YMCA's **LIVESTRONG** program stems from program facilitator's. Without the trainers conducting the program, program effectiveness would be deemed unsustainable and would most likely not be in circulation today. Unfortunately, program trainers have limited knowledge and skills in psychosocial health in order to administer social support for the individuals participating in **LIVESTRONG**. The Massachusetts YMCA's are working

towards implementing a socio-emotional training component within the constructs of the **LIVESTRONG** facilitator training, in order to better equip trainers to handle the emotional stressors coinciding with cancer survivorship.

Program training effectiveness will be measured through cohesion with the program objectives with an emphasis on social and emotional wellness. Identified as a need for cancer survivors, program coordinators will be able to strengthen the **LIVESTRONG** program in the following areas:

- Encouraging the sharing of one's own feelings and experiences with others
- Teaching strategies for survivors to feel less afraid and more hopeful
- Decreasing feelings of isolation while fostering relationships with friends and family
- Improving a support network by forming connections with those who may share the same, or similar experiences

Defining these components for achieving socio-emotional wellness, allows the purpose of this training to measure program facilitator perception and self-confidence in the administration of program social support. **LIVESTRONG** objectives towards improving quality of life, increasing physical activity and promoting health will be attained as one is able to achieve the various components of overall wellness.

Review of the Literature

Support Groups/Cancer Survivorship

Social support can be broken down in ways that address emotion and strengthen one's self-esteem, as well as being informational, direct, and tangible. Social support is identified as a protective factor that influences one's vulnerability to the stressors that impact their overall health (Wong, 2014). An individual can use anyone in their life, a friend, family member,

coworker, etc., when seeking social support, especially those in the process of receiving cancer treatment. What many are not aware of though, is the significance of social support post-treatment; a key component of survivorship.

With cancer survivor demographics on the rise due to advances in medical technology and screening proficiencies, follow-up treatment has become much more significant. Examination of the Follow-Up Care Use among Survivors (FOCUS), studies the role of social support within follow-up treatment to promote self-efficacy in order to strengthen patient knowledge in making decisions in regards to their post-treatment plans (Forsythe, 2014). The assessment of social support affecting patient follow-up care utilized SEDM (self-efficacy for decision-making) in order to measure patient confidence when it comes to taking action of their post-treatment plan towards obtaining optimal health. Forsythe *et al.* cross-sectional survey methodology, concluded that social support has a positive impact to post-treatment planning but is more highly correlated with marital/partnered relationships as opposed to relationships amongst good friends/peers (2014). This can be related to one's perception as most seek emotional stability from their significant other and put their spouse/partner at a higher caliber.

Cancer diagnosis, and treatment of that diagnosis, have long-term effects on an individual's self-esteem and self-efficacy due to everlasting fear of recurrence and the anxiety that results from having minimal control on treatment outcomes. Isolation also has a significant impact on this depreciation to overall well-being. Psychological distress is a result of cancer diagnosis and treatment plans are seeking to incorporate the use of support groups in order to ameliorate the stress that coincides with one's loss of identity; one's "pre-diagnosis" self. Past research, (Davison, Pennebaker, & Dickerson, 2000) concluded that peer support groups are an effective forum of providing psychosocial and emotional support to make improvements towards

psychological well-being (Ussher, Kirsten, Butow, & Sandoval, 2006). Through surveying of cancer support group participants, Mok and Martinson (2000) reported that support group participation produces a sense of empowerment, hope, confidence, and a greater sense of interconnectedness (Ussher et al., 2006). The research conducted by Ussher, Kirsten, Butow, and Sandoval (2006) assessed the impact of the supportive relationships formulated for cancer survivors within specific cancer support groups. This research found that presence of a “cancer family” facilitated improved fostering of friendships by the exchange of intimate and personal, but also relatable, life experiences. This sense of community is accredited to program trainers as they not only are able to provide personal support, but maintain group cohesion (Ussher et al., 2006). Community is able to establish a sense of purpose that those in treatment may not be experiencing in their day-to-day lives. Many family members and friends are unable to feel empathy, so support groups are able to provide a sanctuary that is non-judgmental and accepting of one’s experience. Individuals within cancer support groups have identified the need for an outlet from the emotional overload of “pressure to perform” (Ussher et al., 2006). This construct arises from the influence of others for those in cancer treatment to “keep their chin up,” “stay positive,” etc. By having a support group deemed a “family,” cancer patients are able to feel a sense of belonging within the community, while increasing their ability to cope (Ussher et al., 2006).

Cancer Survivor Needs

Cancer is a disease that affects all aspects of one’s well-being. Whether a diagnosis is caught early or too late, each individual experiences emotion on a spectrum unfamiliar to the typical, healthy person. Those receiving treatment encounter a number of healthcare professionals that they form relationships with as those are the people advancing the road to

remission. According to the American Cancer Society (2016), with the improved screening protocols and advances in technology, cancer survivorship is increasing at substantial rates. With survivorship on the rise, patients in recovery are at a higher risk for developing psychosocial complications due to the lack of engagement with health care providers, family members and friends who had become such avid components of the treatment process. Poorer, general health outcomes can result due to poorly coordinated follow up care that addresses the patient's psychosocial needs (Dhillon, 2015). Data from the National Health Interview Survey (2010) concluded that 1 in 4 cancer survivors do, in fact, report decreased quality of life due to impairments of their emotional and psychological well-being (American Cancer Society, 2016).

When in treatment, one is constantly engaging in human interaction. From old friends reaching out when receiving word of a diagnosis, to family members making time to drive their loved one to a treatment session, and to the nurses and doctors administering the treatments and procedures, cancer patients are consistently being stimulated by other humans. Once in remission, this once perceived level of support, appears to drastically diminish. The Gynecological Outpatient Clinic at Copenhagen University Hospital conducted a person-centered intervention to target the psychosocial needs of cancer survivors, but specifically targeted women who had battled some form of gynecological cancer (Olesen, Duun-henriksen, Hansson, Ottesen, & Andersen, 2016). The intervention was entitled *Guided Self-Determination Gynecological Cancer*, utilizing the theoretical framework of guided self-determination (Zoffmann, 2004), and was aimed at supporting women to have improved self-management skills: self-awareness, communication, interpersonal relationships, decision-making and problem solving (Olesen et al., 2016). This randomized clinical trial concluded that implementation of person-centered led support groups, provided an outlet for these women to effectively

communicate their difficulties and stressors that are negatively affecting their life post-treatment (Olesen et al., 2016). The American Cancer Society identifies the need for survivorship care plans in order for patients continue on to a path for better health; having access to a nutrition plan, physical activity recommendations, and other various remission characteristics (American Cancer Society, 2016). Fear of recurrence hinders patients from being able to feel as though they will ever develop a sense of normalcy and regain the level of quality of life that they once had. Evidence-based programs that facilitate human interaction can aid cancer survivors towards sustaining their remission, while providing them an outlet for emotional overload and an opportunity to receive support.

LIVESTRONG at YMCA

Exercise has been identified as a leading factor in counteracting the side effects of cancer treatment in order improve the overall health and well-being of cancer survivors (Cormie, Peddle-McIntyre, Hayes, Naumann, Turner, Murnane, & Baker, 2015). Physical activity can enhance the body's protective factors to prevent recurrence, decrease fatigue and pain, improve sleep quality, promote self-efficacy, and reduce the prevalence of comorbid conditions (Cormie et al., 2015). More specifically, group exercise can be utilized in follow-up care as it combines the need for physical activity to improve physical health, while simultaneously providing human interaction to enhance emotional stability. The American Cancer Society recommends that post-treatment cancer survivors engage in 150-minutes of weekly moderate-intensity aerobic exercise as well as two, weekly strength training sessions (American Cancer Society, 2016).

The **LIVESTRONG** program at the YMCA (2008) is an evidence-based program that is oriented to emphasize the significance of physical activity after cancer treatment. The **LIVESTRONG** Foundation, originally the Lance Armstrong Foundation, has partnered with the

YMCA's across the country in order to engage cancer survivors in a free, 12-week physical activity intervention in the hope of establishing a baseline of self-efficacy to continue exercising. The sessions are twice a week and led by a certified fitness instructor who also receive wellness training specified towards cancer etiology, treatment and survivorship. A study of the effectiveness of the YMCA LIVESTRONG program was conducted by the Department of Chronic Disease Epidemiology at the Yale School of Public Health and the Dana Farber Cancer Institute. The study aimed at determining program influence on quality of life measures; physical and psychological impact of the program constructs. Increased attendance and participation in the program yielded a positive response to recommended weekly physical activity measures (Fig 1) as well as improvements in quality of life measures and diminished levels of fatigue (Fig 2) (Irwin et al., 2016). Program participation yielded a dose-response effect in participants, in that higher rates of attendance, corresponded with higher perceived quality of life ratings (Fig 2). By attending more program sessions, individuals partaking in LIVESTRONG are able to triple their improvements in cancer-related fatigue compared to those placed into the control group.

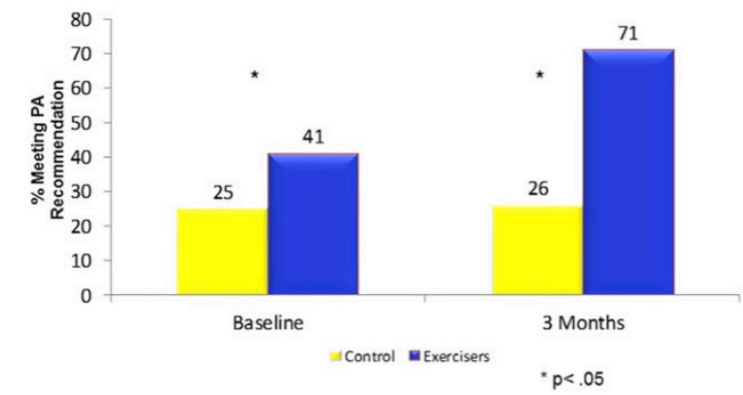


Figure 1: Percentage of Participants meeting physical activity (PA) recommendations at baseline and at three months

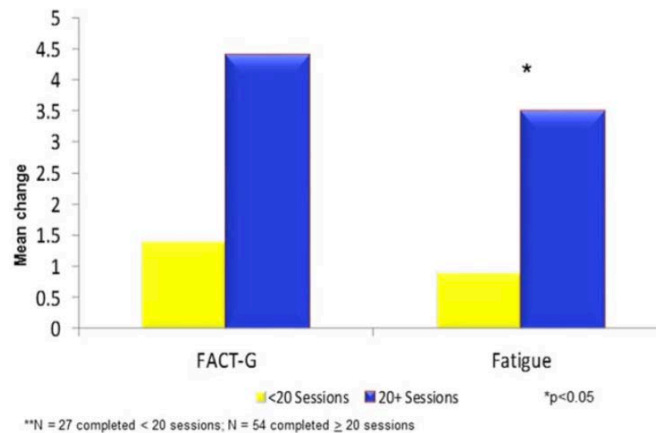


Figure 2: Changes in Functional Assessment of Cancer Therapy-General (FACT-G) and FACT-Fatigue Scales

Mixed methodology confirmed the hypothesis that the **LIVESTRONG** program facilitated by YMCA's is effective in increasing levels of physical activity, improving quality of life, and diminishing various factors of cancer-related fatigue (Irwin et al., 2016). Due to this impact, **LIVESTRONG** has the capacity of targeting a large demographic of cancer survivors throughout the entire country with the large amount of community-based YMCA facilities.

LIVESTRONG facilitators are a vital role for this program due to their continual engagement with participants. They get to know the survivors not only on a client-coach level, but also on a very deep, personal level. Within the past year, the YMCA has been made aware of these facilitator's becoming burnt out as they receive no psychosocial support from the YMCA.

Socio-emotional status of healthcare workers

Socio-emotional health, also known as psychosocial health, is an aspect of development that is established during childhood. This is formulated around one's ability to identify and comprehend one's own feelings within a present situation. Positive experiences and relationships strengthen this aspect of health as a child continues to develop and is able to effectively communicate their own emotions; while reciprocally comprehending the emotions of those

around them. Once this skill is attained, children are able to foster social support to enable their development further into young adulthood.

The stressors of working with sick individuals can have a significant impact on the overall health of those in the healthcare profession. With inconsistent schedules and long hours, self-care is often not a priority and emotional overload may ensue. Healthcare professionals, whether working at the clinical or community levels, have to manage emotion in a way that is socially appropriate in any given situation. Often times, personal factors must be omitted, or suppressed, in order to sustain professionalism. The mental and emotional health of those in this field is often compromised and can lead to poor levels of self-efficacy. This concept is identified as emotional labor, as it requires the body to work hard in order to exhibit minimal levels of emotion. This results in what is identified as burnout; when labor demands exceed the resources available to an employee (Lings, Durden, Lee, & Cadogen, 2014). Burnout increases when an employee's work overload increases along with the socio-emotional demands of one's job. Maslach and Jackson (1981) identified the three major components of burnout as emotional exhaustion, depersonalization and reduced personal accomplishment (Lings et al., 2014). Depersonalization and reduced personal accomplishment are both results of overall emotional exhaustion, but all co-exist in the presence of workplace stress; they are causal to one another. One experiencing emotional dissonance reaches a threshold when outlets for those emotions are unachievable; resulting in psychological stress and poor workplace performance.

The concept of compassion fatigue is a common theme amongst those who care for patients that are experiencing severe trauma or stress; an empathetic human response. The two major constituents of compassion fatigue include secondary traumatic stress, which arises from the desire of wanting to help a person in need, and burnout, which consists of physical,

emotional and mental factors (Zeidner, Hadar, Matthews, & Roberts, 2013). Secondary traumatic stress has been linked to having similar effects on the body similar to Post-Traumatic Stress Disorder, in that a traumatic experience results in natural, consequent behaviors and emotions to an event (Merriman, 2014). Socio-emotional and operational demands, specifically in terms of role overload, have been identified as the determinants of stress in the workplace that predict that onset of burnout within an individual (Lings et al., 2014). Figley and Kleber (1995) identified two theoretical perspectives within compassion fatigue in order to assess the causation of this relatively new phenomenon in healthcare work. The first being resource depletion and the second being emotional contagion. In resource depletion, burnout arises simply from exposure to the patient who is experiencing some form of distress, while emotional contagion is relative to one's emotional response to the traumatized person (Zeidner et al., 2013). One's susceptibility to compassion fatigue may be strongly correlated to one's own emotional intelligence. Specifically, how one is able to regulate their own emotions in response to daily experiences and their surrounding environment. Effective coping strategies are able to strengthen one's ability to handle stress and emotional overload by knowing how and where to access the appropriate resources. Utilization of Hobfoll's (2011) Conservation of Resources theory, addresses and concludes that vulnerability to compassion fatigue increases as stressful events consume resources that would otherwise enhance their coping skills (Zeidner et al., 2013). Higher levels of emotional intelligence are able to support one's ability to defer compassion fatigue if they are able to regulate their own emotions appropriately.

Building Resiliency

Often times, cancer patients come out of treatment and want to jump right in to old routines and regain the level of normalcy that had since been taken away. This is because cancer

survivors have a resiliency unlike anyone else in the world; they are strong fighters with admirable levels of mental toughness. When transitioning back into home life, health care providers are working on promoting the growth of whole-patient care; implementing the psychosocial care of patients and their families (Rosenberg, Baker, Syrjala, Back, & Wolf, 2013). The aim of highlighting family participation within the constructs of follow-up treatment, can promote a sense of purpose and reduce levels of helplessness that they may have developed for their loved one (Rosenberg et al., 2013). Family members also possess resiliency as it is their goal to establish normalcy for the patient as they return home.

Although family plays a vital role in the post-cancer treatment plan, cancer patients do not always deem said family members as valuable assets to their continuity of care. Often times they can become too emotionally invested or too over sensitive to the person's needs. This is when support groups can become the most significant part of a patient's remission, as they can be surrounded by individuals who have no preconceived notions of one another. **LIVESTRONG** program facilitators are a major contributor to building resiliency not only for cancer survivors, but for themselves as well. Being able to adapt with the present environment, can elicit positive psychosocial outcomes that can be adopted by the individuals around you (Rosenberg et al., 2013). Physicians at the Seattle Children's Hospital conducted a study reviewing the resiliency of parents and caregivers of those whose child was battling cancer. Findings from this study concluded that resiliency is a critical component of psychosocial care, while flexibility in adverse situations can enhance and sustain resiliency levels (Rosenberg et al., 2013). Resiliency is adopted over time and can grow as a person is more adaptable to their surroundings. By implementing whole-patient care into the **LIVESTRONG** program, facilitators not only become a part of the coping and healing process, but they can also promote the balance between physical,

mental, emotional and social health in a way that may not be provided for the program participant in daily life. Resiliency matters and highlighting this phenomenon can make a significant impact for the **LIVESTRONG** program and all of its participants.

Study Model/Summarization:

Facing Cancer Together is a Boston based organization consisting of clinical psychologists whose aim is to provide support group sessions for cancer survivors and their families. Through educational programs, *Facing Cancer Together* is able to facilitate engagement of cancer survivors to collaborate with one another and to realize that they are not alone in their journey. This organization has partnered with the YMCA in order to conduct the **LIVESTRONG** program training; enhancing the synergence between community and health outreach program providers.

Through use of a mixed methodology, analysis and evaluation of the **LIVESTRONG** facilitator's can be reviewed in order to describe socio-emotional health behaviors. Trainers can reach an emotional overload when working with cancer survivors as their stories of perseverance and resilience can elicit a multitude of emotions. Synthesis of the acquired data will allow for further elaboration of improving the overall well-being of program facilitators. The foundational evidence-base that has established the YMCA **LIVESTRONG** as one of the organizations most successful EBHI, (evidence-based health intervention) provides validity of program effectiveness. In order to further evaluate the program, constructs must be broken down for analytical review. Gaining perceptions of program components from program facilitators, can provide further insight on how to adapt the program to increase sustainability, not only through the state, but also throughout the country.

The purpose of this study is to evaluate **LIVESTRONG** at the YMCA program facilitator effectiveness when disseminating social support, while simultaneously adopting strategies to sustain a healthy psychological equilibrium. Through the adoption of *Facing Cancer Together* social/emotional training, the **LIVESTRONG** program facilitator's will adopt skills targeted in coping strategies for support group implementation into the **LIVESTRONG** program.

Methodology

Participants

LIVESTRONG coordinators were provided the opportunity to participate in a free, social and emotional training with leaders in cancer support. Fifteen **LIVESTRONG** facilitators participated in the training and were given the opportunity to contribute to the study, provided their consent (See Appendix A). The study recruited nine participants, who were asked to complete a pre and post-training evaluation by the study facilitator. This evaluation will assist in strengthening the necessity of a socio-emotional training to be further adapted and implemented within the **LIVESTRONG** at the YMCA program.

Measures

Measures collected throughout this analysis were targeted towards facilitator perceived effectiveness of socio-emotional training implementation. Once informed consent from study participants had been obtained by the study facilitator, study measures were ensued. Program measures for the nine study participants were collected via pre-training and post-training survey questionnaire. Six weeks after the training, participants were contacted to participate in follow-up interviews. This measure was used to assess the implementation and success of the socio-emotional training in their **LIVESTRONG** programs sessions as well as their own personal social and emotional well-being.

Program Training Participant Measures. A nine-question survey was administered at the beginning of the program training (See Appendix B). This pre-test evaluation consisted of six Likert-scale questions along with three open-ended questions. These questions were aimed at assessing the trainer's knowledge and perceptions of socio-emotional health and wellness dimensions as they pertain to the **LIVESTRONG** program. These measures evaluated the knowledge of those facilitating the **LIVESTRONG** program and where their strengths and weaknesses are in terms of social support strategies. Examples of these questions included:

1. On a scale of 1-5, what are your perceptions of the significance of social/emotional health?
2. On a scale of 1-5, how do you feel your skills are in fostering social support as part of the **YMCA LIVESTRONG** program?

The nine participants completed an eight-question survey assessment of their feelings and perceptions post program training (See Appendix C). The assessment consisted of five-Likert scale questions along with three open-ended questions. By conducting the assessments within the same day, the data can analyze the initial impact and significance of the training. Examples of these questions included:

1. On a scale from 1-5, this training was helpful to me and will benefit my current **LIVESTRONG** program.
2. On a scale of 1-5, I have gained a better understanding of what social/emotional health is and how it pertains to cancer survivorship.
3. On a scale of 1-5, I believe that social/emotional training will have a significant impact on the **LIVESTRONG** program at the YMCA.

After six weeks, participants were contacted to participate in follow-up interviews within eight weeks of the program training; only three participants were recruited to participate in follow-up interviews. The interview questions evaluated and reviewed how the socio-emotional component is being implemented and how effective this additional construct is to program sustainability. Examples of interview questions included:

1. How has your confidence facilitating social support increased?
2. How are you feeling emotionally since receiving the program training?
3. What feedback have you received, if any, from program participants on spiritual or emotional wellness?

Procedure

The study was determined to be expedited by the Merrimack College Institutional Review Board. Participants participated in the social/emotional training on February 10, 2018. The study facilitator connected with training participants via email one week prior to training day. The training participants were provided a copy of the consent form in order to review and complete prior to the study. Some participants were recruited at this time while others were recruited on the day of the study. On the day of the study, the study facilitator administered the pre-assessment questionnaire in order to assess feelings and perceptions of their current skills and knowledge of cancer survivorship, wellness, and social/emotional well-being. After the five-hour long training session, a post-assessment questionnaire was administered by the study facilitator in order to retrieve accurate and instantaneous participant feelings and perceptions. Six weeks after the training was completed, the study facilitator connected with participants to conduct follow-up interviews. The study facilitator travelled to program sites to conduct the interviews and to evaluate the benefits and improvements of and for a social/emotional training.

Project Timeline

Recruitment	January 2018	Chosen by MA Alliance of YMCAs
Retrieval of Informed Consent	February 2018	Completed by study facilitator
Pre-training survey	February 2018	Completed by study facilitator
Post-training survey	February 2018	Completed by study facilitator
Follow-up interviews	March 2018	Completed by study facilitator

Data Analysis

Survey responses were coded manually by study facilitator and participant identity remained confidential. Synthesis of the data provided an understanding of current program coordinator confidence and self-efficacy in social support facilitation, as well as the effect of socio-emotional training for coordinators of the YMCA LIVESTRONG program.

Outcomes

LIVESTRONG at the YMCA is already established as an evidence-based program as previous research, conducted by the Yale Cancer Center and the Dana Farber/Harvard Cancer Institute, has concluded that participants experience improved levels of fitness and quality of life, while also experiencing decreased levels of cancer-related fatigue (Irwin et al., 2017). The present evidence supports the claim that LIVESTRONG has a significant impact on cancer survivorship throughout the country and can only continue to grow in support of its mission of improving the quality of life of those affected by cancer. The purpose of this study was to examine the effectiveness of the socio-emotional component of LIVESTRONG coordinator program training and the coordinators experience throughout the training, in order to further implement social support within the YMCA LIVESTRONG program. Findings of this evaluation are to be reviewed by the Massachusetts Alliance of YMCA's and YMCA of the USA

in order to determine the need for further social and emotional interventions into program trainings.

Results

Quantitative Data

Out of the 15 program training participants, 9 agreed to participate in the study; a 60% participation rate. The sample size was 100% Caucasian females ranging from 40-60 years old. In order to support the qualitative data, quantitative data were used to establish program facilitator perceptions of knowledge of social/emotional health. A summary of the knowledge and perceptions of program facilitators pre and post of the program training is presented in the table (*See pg. 20*). The pre and post questions were not identical, so correlation analysis could not be conducted.

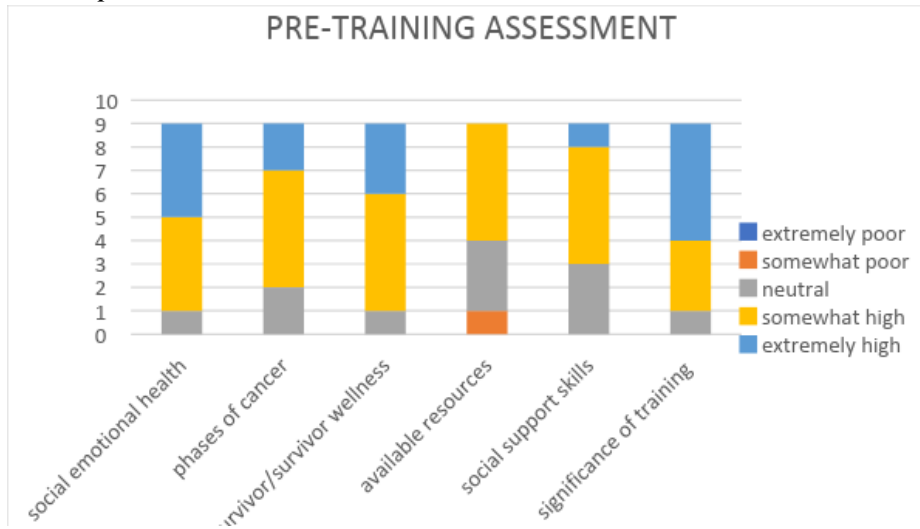
Descriptive statistics show that facilitators are quite knowledgeable in the significance of social/emotional health, survivor and survivor wellness, and the phases of cancer, but reported more limited knowledge in resources to handle emotional overload and orchestrate a social support; graph 1 highlights these responses (*See pg. 21*). Participants expressed that the training would be effective towards enhancing their skills as program instructors. Post-training assessment confirmed that the impact of program training was extremely effective as 66.7% of participants selected the highest, most positive ranking on the five categories being analyzed. The average of all assessment questions was between 4.78 with a standard deviation of 0.44; representing strong perceptions of program training benefits; graph 2 highlights these responses (*See pg. 21*).

Table
Likert Scale Question Results
 (n=9)

Question	PRE		Question	POST	
	<i>M</i>	<i>SD</i>		<i>M</i>	<i>SD</i>
Perceptions of the significance of social/emotional health	4.33	0.71	Benefits of the training for the LIVESTRONG at the YMCA Program	4.67	0.50
Understanding the phases of cancer	4.00	0.71	Gained a better understanding of social/emotional health as it pertains to cancer survivorship	4.78	0.44
Understanding the word survivor and what survivor wellness looks like	4.22	0.67	Feeling better equipped to cope with emotional stressors within myself as well as with program participants	4.67	0.50
Possessing the tools, knowledge, and resources to prevent becoming emotionally overloaded when working with cancer survivors	3.44	0.73	Social/emotional training will have a significant impact on the LIVESTRONG Program at the YMCA	4.67	0.50
Skills in fostering social support as part of the YMCA LIVESTRONG program	3.78	0.67	Would like to receive further training in social/emotional health	4.67	0.50
Importance of the social/emotional training towards working with people with cancer	4.44	0.73			

Note: Response choices were 1= extremely low, 2= Somewhat low, 3= neither high/low, 4= somewhat high, 5= extremely high

Graph 1
Pre-assessment Responses



Graph 2
Post-assessment Responses



Qualitative Data

Figure 3 (See pg. 24) provides an overview of the common themes and subthemes from data analysis. The major themes include the need for social/emotional support strategies, enhancing participant connectedness, and establishing self-care. Post-follow up interviews

addressed more components for growth and future directions of the program. The training intervention elicited as a gateway for areas in social/emotional health that can be implemented into further trainings for LIVESTRONG facilitators. Descriptions from the data are presented below.

Support Strategies. Cancer survivors, and those enrolled in the LIVESTRONG at the YMCA program, need an immense amount of support not just physically, but also emotionally. Participants went into the training with the perception that they need additional assistance in their pursuit of being able to provide social and emotional guidance not only for program participants, but also within themselves. Study participants addressed their concerns that they feel they have a hard time being emotionally “tough” for program participants when approached by their post-treatment stories and current lifestyle. Participant 7 addressed a future goal of the LIVESTRONG program “to be able to help participants become emotionally stronger, by in turn, becoming an emotionally stronger trainer.” Participants also provided insight to connect with outside, local support organizations to aid their members in their survivor journey. Forming these partnerships could allow program sessions to have guest facilitators be able to lead discussion-based, support groups to focus on spiritual and/or emotional health; moving beyond just the physical activity component. Participant 6 addressed wanting to “continue to find ways to get people to talk” during program sessions and permitting them to tell their story.

Participant Connectedness. The LIVESTRONG at the YMCA program runs for a limited amount of time. The hope for participants is that once the program ends, they will transition to becoming Y members. Although the retention rates are high for this program, it is not always the case. Many facilitators expressed that having to graduate their participants and potentially never see them again is emotionally debilitating. Many LIVESTRONG programs are

additionally running post-graduate programs in their free time in order to continue to provide for program participants as they have become so invested in the program and have gained a heightened sense of purpose. Participant 9 explains:

“I would like to learn the appropriate responses and phrases to use (or not use) in a variety of situations, as words hold so much weight when chosen properly. Also, being able to identify when survivors may need additional services and/or support and then guiding them towards such services would be a key goal.”

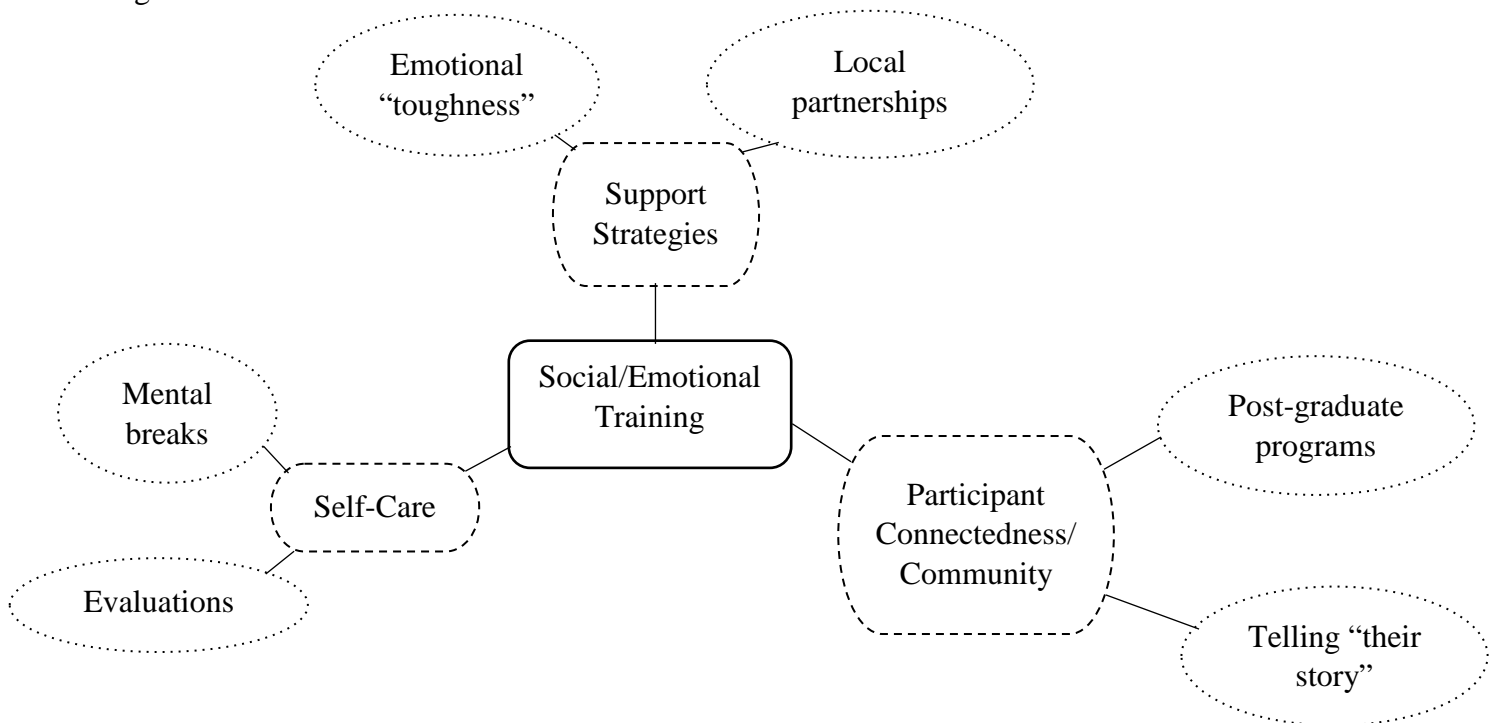
Survivors want an outlet, but they also want to talk about what they have gone through, are going through, and what they expect to go through. Participant 5 explained that “letting the survivors talk about whatever is on their mind is beneficial.” The training provided an opportunity for study participants to be in a space similar to this. The group was able to share stories and be in an environment with a room filled with individuals who were there to listen. Participant 7 noted how “simple it can be to create a safe space,” while being able to utilize the team dynamic that is formed at such an early stage. Participants can connect and relate to one another, so finding the time to incorporate this program component, will hopefully increase engagement and provide survivors a safe space to share their feelings without feeling the burden of inconveniencing close friends or family.

Self-care. The need for facilitator self-care in order to avoid emotional overload, was addressed by a number of participants. Many explained that they let their emotions get the best of them and feel ill equipped to handle the stressors that coincide with the population they are working with. The training was able to promote that these feelings are okay, but you need to be more self-aware and know when to take mental breaks in order to recharge. Many participants are individuals who are survivors themselves and completed the YMCA LIVESTRONG program; they became facilitators because they were so devoted to the program. Participant 7

wants to be able “to take care of [her]self emotionally in order to provide stronger support for members.” Participant 3 stated “I need to be more present in the moment, while also finding ways to support my staff and myself.” Many facilitators are so invested in their survivors that they often forget the significance of their own, emotional health. Participant 1 explained that training re-assured “I do want to do this job and I have a great support system at my Y.”

Checking-in with one another and being evaluated from LIVESTRONG participants was a common theme in order to promote and sustain self-care of program facilitators.

Figure 3: Themes and Subthemes



Post Training Follow Up Interviews. Six weeks after the program training, participants were contacted in order to review and discuss the impact of social/emotional wellness training. Out of the 9 study participants, 3 agreed to participate; a 66% dropout rate from those who initially participated in the training day assessment. Participants discussed common themes that were identified when reviewing the interview data: interpersonal relationships, recurrence, grief.

The development of interpersonal relationships amongst participants and trainers is inevitable over the course of a LIVESTRONG session. Participants described this component as incredibly natural as they want to be invested in the journey with them. These strong interpersonal relationships are then aimed at member retention and a challenge of the program is keeping LIVESTRONG participants engaged with the Y once the program has ended. From this comes the next concern of facilitators in terms of cancer recurrence in program participants. This aspect of the disease is something that facilitators feel needs to be better supported as their participants have become family to them. Not all LIVESTRONG members remain cancer free forever, so facilitators have to deal with loss.

“I have reconciled that we can’t change that they died, but the impact we had on them while they were alive, that they invited us and allowed us to be a part of their lives, I get comfort from that.”

Participants 2 and 3 addressed their future hope for the program training to be more of a workshop that emphasizes the various ways to handle grief; how to avoid compartmentalizing loss and how to work through those stages. They are seeking a training where they could be provided more tools and skills that could either be adopted on an individual or group level.

Participant 2 stated:

“Having someone else be able to run a session, whether it be meditation or a yoga practice, to release the stress that we internalize. We don’t take the time to care for ourselves in that way.”

Discussion

The current study evaluated the significance of social/emotional training for facilitators who are running LIVESTRONG at the YMCA programs throughout the state of Massachusetts. Study participants have become so dedicated to the work, that their priorities have strayed from self-actualizing their significance as a program facilitator. Putting the social/emotional training to

practice shed light on the need for more sessions for trainers to decompress and be educated on emotional cognition and mindfulness. Major findings of the study concluded that the participants, as facilitators, felt that they need more support and training towards how to cope with the emotional overload that coincides with working with those living as survivors. This program evaluation was consistent with the study hypothesis that the training would be beneficial to study participants to further expand the social/emotional health skills and coping strategies in order to adapt program sustainability; reducing facilitator turnover and improving overall mental wellbeing.

Overview and Interpretation of Findings

The results show that social/emotional training does benefit trainer self-efficacy in administering social support. Program facilitators do feel the need to receive trainings such as this in order to improve performance and enhance the experience of program participants in the **LIVESTRONG** at the YMCA program. Pre and post assessment surveys found statistically significant improvements in study participant perception of training. Interviews identified areas of future growth for interventions such as this, as it pertains to emotional wellbeing for program participants, as well as program facilitators.

“I am very sensitive to the emotions of others. I cry very easily when hearing some persons struggles with chronic illness. I want to better be able to handle these types of situations so that I can be an effective leader in the program, without showing too much of my own emotions.”

Findings also showed that at the end of the 12-week program, facilitators experience compassion fatigue as they develop fear of the unknown of what happens next for program participants. There is a lot of need for the implementation for post-graduate programs.

“If you do your job really well and your Y provides programming afterwards that adds value to membership, those interpersonal relationships can be cultivated, and membership is a side benefit.”

LIVESTRONG participants have developed deep, personal connections to not only program facilitators, but also to their fellow LIVESTRONG participants. For many, once LIVESTRONG ends they are not as motivated to attend the YMCA because they are not seeing their same group of friends and do not want to exercise alone. The cohesion and team dynamic that arises from the LIVESTRONG program is comparable to that of a family, so it can be an incredibly emotional part of the process when program participants graduate and trainers are no longer a frequent part of their lives.

Correlation to the Literature

Results of the study revealed that the strength of interpersonal relationships formed within this program create emotional obstacles for program participants and program facilitators. The findings are consistent with the research hypothesis that the social/emotional training for facilitators is beneficial and effective for program growth. Expanding psychological workshops will be an added benefit for the individuals running the program. These findings are consistent with the literature that one's emotional labor can be compromised; resulting in emotional overload. Participants of the study identified their lack of self-care due to their commitment and passion to their LIVESTRONG participants. This level of emotional exhaustion prevents one from doing their job to the best of their abilities. Study findings can initiate further trainings on mindfulness and social/emotional health that can provide program facilitators strategies on how to prevent emotional overload and psychological distress.

Study findings also support research findings that are consistent with building resiliency amongst program participants. The LIVESTRONG program provides individuals a safe space to laugh, cry and take their life back. Being able to build these individuals back up and encourage their journey to better health while promoting resiliency post-treatment, is vital to an individual's

psychosocial care. The environment of **LIVESTRONG** yields this effect amongst participants due to the support being provided. In order to add value to membership and continue engagement, resiliency of the survivors must be built up. This is orchestrated by the program facilitator and establishes the environment for ultimate client success.

Strengths and Limitations of the Study

Collecting quantitative and qualitative data provided significant findings for this research in terms of evaluating effectiveness. Descriptive statistics were able to provide the baseline of study participant perception, while discussion-based interviewing gave insight on training significance as it pertains to program stability. The methodology is the strength of the study as the data could be supported by personal experiences to make the data applicable and establish opportunities for social/emotional stability in **LIVESTRONG** facilitators.

The primary limitation within this study is the small sample size of participants. The participation size was selected from a relatively low group size (n=9 out of 15 who attended the training), but a 100% participation rate was not anticipated. The demographic of the study was also a disadvantage. Only being able to sample female feelings and perceptions accounts for more of a biased opinion; a one-sided directional view. Granted there are not many male **LIVESTRONG** facilitators, but there would be more of a perspective if both genders were present in the sample group. There was also a 66.67% dropout rate from those who participated in survey assessments on the day of the training, to those who participated in follow-up interviews; only three participants out of the nine in the sample. More follow-up data would have been beneficial towards assessing the impact of the intervention.

Another limitation of the present study is that some of the participants are cancer survivors themselves and graduates of the **LIVESTRONG** program. These individuals have

more of a solid foundation of social and emotional wellness as it pertains to the phases of cancer and its treatment. These individuals also possess a more relatable perspective and are more emotionally connected to the program, as opposed to those who are not cancer survivors.

Future Directions for Research

Future research should be conducted to see which YMCA's are already offering post-graduate programs and to evaluate the additional work they are doing for **LIVESTRONG**. Study participants identified the need for program participants to have more survivorship outlets available at the Y considering many do become YMCA members after completion of the program. Analyzing the impact of the post-graduate programs and assessing their significance amongst **LIVESTRONG** participants can provide an evidence base towards the incorporation of emotional wellness. Facilitators identified a strong interpersonal connection to the **LIVESTRONG** participants and stated that there are so many additional emotions that tie into the program. These individuals are in such a vulnerable state and **LIVESTRONG** provides them an outlet to feel like themselves again and to be around other individuals who they can relate to. Once this program ends, those connections are harder to maintain because the sessions are over and facilitators have new sessions beginning. Study participants suggested developing post-graduate programs that are led by graduates of **LIVESTRONG** in order to sustain a group setting that encompasses what it means to be surviving.

Future research should also look to analyze the benefits of grief training. In the follow-up interviews, one participant identified the lack of knowledge and resources around what happens when a program participant passes away. The reality of cancer is still present and there is not always a happy ending. Recurrence is quite common and sometimes happens to an individual who is currently a **LIVESTRONG** participant. Facilitators have to experience devastating loss

and it can be too much to handle. Based on the literature, emotional overload can stem from various environmental factors that cause stress on one's mental and emotional state. Analyzing grief and how it impacts not only program facilitators, but also program participants, could provide insight on how to provide the right type of counseling services. Pinpointing the stressors for a LIVESTRONG program facilitator, could establish the aspects of support they need in order to run an even better program and improve their overall performance.

Practical Applications

Findings of the present study shed light on social and emotional wellness as a benefit to individuals working with cancer survivors. Those working with this demographic, need the tools and skills to cope with the stress and grief that arise when sharing the journey with those who are surviving from cancer. The emotional toll of patient treatment, recurrence, and sometimes death, is why it is important for organizations to expand facilitator accessibility to mental health services and/or workshops. Past literature has shown that workplace performance decreases when one is emotionally and psychologically exhausted. Burnout prevents healthcare workers from doing their job to the best of their ability and the lack of personal accomplishment compromises self-esteem. Organizations need to evaluate their resources for their employees that do this type of work. Although, LIVESTRONG is still a job, there is a much deeper rooted, personal connection that arises. Individuals come to this program seeking to improve personal fitness, to then discover that they have found a group of people who they can sweat, laugh and cry with; building interpersonal relationships during an incredibly difficult transition period of their treatment life.

The significant strength of the present study is the identified need for more social/emotional development programs amongst LIVESTRONG facilitators. Because there is

such a strong emotional component in **LIVESTRONG**, facilitators are looking for more resources on how to cope with the emotional roller coaster they experience during the 12-week session. Responses from study participants were consistent with study aims and seeking to measure training effectiveness. Insight from study participants will provide an avenue for further conduction of psychological trainings. Results promote the need for **LIVESTRONG** to go beyond a physical activity program; incorporating social and emotional wellness in order to strengthen the objectives of the program.

Conclusion

The term “survivor” has a multitude of meanings and is not universal. This term, although commonly associated with remission, is for all individuals impacted by cancer. Those who are living and thriving are survivors, those who push harder every day are survivors, these individuals are surviving with and without cancer. This point was shared across study participants and has become a common theme for **LIVESTRONG** at the YMCA facilitators. They push for placing a survivor in the present and also deem themselves warriors, not simply survivors. The present study seeks to yield more opportunities to enhance survivorship as it pertains to social and emotional health for **LIVESTRONG** facilitators. Their increased perceptions and knowledge of how to handle their emotional labor, will improve their skills as instructors in order to better facilitate social support amongst program participants.

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Appendix

Appendix A: Letter of Informed Consent

INFORMED CONSENT

Evaluation of YMCA LIVESTRONG Program Training

You are being asked to take part in a research study of how the addition of socio-emotional training in training LIVESTRONG coordinators is effective towards the overall success of the program. Please read this form carefully and ask any and all questions you may have before agreeing to take part in the study.

What the study is about:

The purpose of this study is to evaluate the effectiveness of the socio-emotional training component of the YMCA LIVESTRONG program.

What we will ask you to do:

If you agree to be a part of this study, you will be asked to complete a survey and participate in two interviews with the study facilitator. The survey and interview will include questions about your feelings, perceptions, and knowledge of social and emotional health. There will also be questions about the LIVESTRONG program. The survey will take no longer than 10 minutes and the interview will take about 30 minutes.

For the accuracy of data collection and to ensure that remarks made are accurate, the interview sessions will be audio recorded. These recordings will be transcribed with no personal identifiers included, and will then be destroyed. If you are not comfortable being audio recorded please inform the investigator prior to starting the interview. It is your right to not be recorded if you so choose.

Risks and Benefits:

There are no inherent physical risks in the procedures themselves, and it is not anticipated that participants will experience risks in completing the interviews. Participants will not be exposed to any more risk or harm of discomfort than those ordinarily encountered in daily life. This study may be of no direct benefit to you, but it will improve our knowledge of trainer effectiveness for the participants of the LIVESTRONG program at the YMCA.

Your answers will be confidential:

The records of this study will be kept private. Identities of study participants will remain anonymous and will not be used in any reports or publications of this study.

Taking part is voluntary:

Taking part in this study is completely voluntary. You may skip any questions that you do not want to answer and you are free to withdraw from the study at any time. A decision not to participate will not adversely affect any interactions with the investigator or any representative/employee of Merrimack College.

Questions:

Before you sign this form, please ask any questions on any part of this study that is unclear to you. You may take as much time as necessary to think it over. At any point in the study, you may question the Principal Investigator about the study (Alyssa LaMonica, 978-764-7088, lamonica@merrimack.edu). In addition, you are free to contact the Institutional Review Board Chair, with any questions (irb@merrimack.edu).

Statement of Consent:

This project has been explained to me to my satisfaction, in language I can understand, and I have received a copy of this consent form. I understand what my participation will involve and I agree to take part in this project under the terms of this agreement. I understand that I am not giving up my legal rights by signing this form.

 Signature of Participant

 Date

 Printed Name of Participant

 Signature of Investigator/Designee Obtaining Informed Consent

 Date

Appendix B: Pre-Training Assessment Questionnaire

Pre-assessment Questionnaire

On a scale from 1-5, please answer these short survey questions to the best of your prior knowledge and perceptions in the following areas:

1. What are your perceptions of the significance of social/emotional health?

1	2	3	4	5
Extremely Low	Somewhat Low	Neither High or Low	Somewhat high	Extremely high

2. How well do you understand the phases of cancer?

1	2	3	4	5
Extremely poor	Poor	Fair	Somewhat well	Extremely well

3. How well do you understand the word survivor and what survivor wellness looks like?

1	2	3	4	5
Extremely poor	Poor	Fair	Somewhat well	Extremely well

4. To what extent do you agree or disagree that you have the tools, knowledge, and resources to prevent becoming emotionally overloaded when working with cancer survivors?

1	2	3	4	5
Strongly disagree	Disagree	Neither Agree or disagree	Agree	Strongly agree

5. How do you feel your skills are in fostering social support as part of the YMCA LIVESTRONG program?

1	2	3	4	5
Extremely Low	Somewhat Low	Neither High or Low	Somewhat high	Extremely high

6. Based upon what you know of this training, how important do you think it will be to your work with people with cancer in the YMCA LIVESTRONG program?

1	2	3	4	5
Strongly disagree	Disagree	Neither Agree or disagree	Agree	Strongly agree

Please provide detailed and thorough responses to the open-ended questions listed below to the best of your knowledge:

1. What are your future goals for the LIVESTRONG program?
2. How have you approached the challenges presented by program participants? Specifically when discussing mental and emotional health.
3. To the best of your knowledge on social/emotional health, what results are you hoping to gain from this social/emotional training?

Appendix C: Post-Training Assessment Questionnaire

Post-assessment questionnaire

On a scale from 1-5, please reflect on the following statements based on your feelings/perceptions of the psychosocial training listed below:

1. This training was helpful to me and will benefit my current LIVESTRONG program.

1	2	3	4	5
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Strongly disagree	Disagree	Neither Agree or disagree	Agree	Strongly agree
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2. I have gained a better understanding of what social/emotional health is and how it pertains to cancer survivorship.

1	2	3	4	5
Strongly disagree	Disagree	Neither Agree or disagree	Agree	Strongly agree

3. I feel better equipped to cope with emotional stressors within myself as well as with program participants.

1	2	3	4	5
Strongly disagree	Disagree	Neither Agree or disagree	Agree	Strongly agree

4. I believe that social/emotional training will have a significant impact on the LIVESTRONG program at the YMCA.

1	2	3	4	5
Strongly disagree	Disagree	Neither Agree or disagree	Agree	Strongly agree

5. I would like to receive further training in social/emotional health as it pertains to LIVESTRONG at the YMCA.

1	2	3	4	5
Strongly disagree	Disagree	Neither Agree or disagree	Agree	Strongly agree

Please provide detailed and thorough responses to the following questions listed below:

1. What are 3 takeaways from the social/emotional training that you hope to utilize in your LIVESTRONG program?
2. How do you plan on improving the social/emotional health of program participants and instructors? How are you hoping to make these aspects of your program effective?
3. How are you going to track your progress and success? What are some measures you want to utilize to validate your performance?

Appendix D: Follow-Up Interview Questions Framework

These questions were used to lead a discussion, further questions were elicited dependent on the context of the conversation with study participants.

1. What are the most effective components of your LIVESTRONG program? What components need improvement?
2. How has your confidence facilitating social support increased?
3. How are you coping with the kinds of emotions/responses you are eliciting from program participants?
4. How are you feeling emotionally since receiving the program training?
5. Many of you are graduates of the LIVESTRONG program, how do you feel that has impacted your journey as a program facilitator? Do you believe it alters your ability in a way that hinders your performance or makes it better?
6. What feedback have you received, if any, from program participants on spiritual or emotional wellness?
7. What further evaluating would you like to see in the future?